

## Prenatal genetic counseling in cross-cultural medicine

### *A framework for family physicians*

Ashvinder K. Bhogal MSc MS Fern Brunger MA PhD

#### Case description

Naseem, who immigrated to Canada from Qatar 3 months ago, is 33 years old (gravida 7, para 4, aborta 2) and 10 weeks pregnant. She is being seen by Dr Abraham—an experienced family physician and Naseem's new family doctor. Dr Abraham adeptly completes a prenatal checkup. As part of a routine prenatal checkup, she discusses prenatal screening with Naseem, including its risks and benefits. Naseem's comprehension of English is limited. Owing to the time-sensitive nature of the discussion and decisions around prenatal testing, Dr Abraham rushes through the explanation more so than she would normally. Throughout the discussion of risks and benefits, Naseem nods frequently. Believing she has obtained informed consent, Dr Abraham sends Naseem for a blood test and ultrasound in a week's time. Dr Abraham receives the results a week after the tests are completed, notes that the results show an increased risk of Down syndrome at a rate of 1 per 100 live births, and requests Naseem's return.

This time Naseem arrives with her husband, who is concerned that his wife has been called back so soon after her previous appointment. Dr Abraham, wishing she had more time but realizing she must use the little time she has as efficiently as possible, proceeds to explain to them that their child has an increased risk of having Down syndrome and that, if they wish, a chorionic villus sampling or an amniocentesis could be performed to confirm or disprove whether their child has Down syndrome. Dr Abraham believes she has fully informed them and waits for the couple's response.

After several minutes of discussion in their mother tongue, Naseem's husband asks: "Doctor, how do you know all this? We would have preferred to never have known this. My wife always discusses with me what was done at the doctor's office, but she never mentioned this test to me. Neither of us had any idea it was being done. We do not believe in abortion; however, we also do not believe in not using the knowledge we have for the good of our baby and our family. How could you put us in this position?"

This article has been peer reviewed.  
Cet article a fait l'objet d'une révision par des pairs.  
*Can Fam Physician* 2010;56:993-9

#### Abstract

**OBJECTIVE** To help family physicians practise effective genetic counseling and offer practical strategies for cross-cultural communication in the context of prenatal genetic counseling.

**SOURCES OF INFORMATION** PubMed and the Cochrane Database of Systematic Reviews were searched. Most evidence was level II and some was level III.

**MAIN MESSAGE** The values and beliefs of practitioners, no less than those of patients, are shaped by culture. In promoting a patient's best interest, the assumptions of both the patient and the provider must be held up for examination and discussed in the attempt to arrive at a consensus. Through the explicit discussion and formation of trust, the health professionals, patients, and family members who are involved can develop a shared understanding of appropriate therapeutic goals and methods.

**CONCLUSION** Reflecting on the cultural nature of biomedicine's ideas about risk, disability, and normality helps us to realize that there are many valid interpretations of what is in a patient's best interest. Self-reflection helps to ensure that respectful communication with the specific family and patient is the basis for health care decisions. Overall, this helps to improve the quality of care.

#### Résumé

**OBJECTIF** Aider le médecin de famille à dispenser un counseling génétique efficace et lui suggérer des stratégies de communication interculturelle pratiques pour y arriver.

**SOURCES DE L'INFORMATION** On a consulté *PubMed* et la *Cochrane Database of Systematic Reviews*. La plupart des preuves étaient de niveau II, quelques-unes de niveau III.

**PRINCIPAL MESSAGE** Les valeurs et croyances des médecins autant que celles des patients sont déterminées de façon culturelle. Pour favoriser le meilleur intérêt des patients, les idées préconçues du patient comme celles du médecin doivent être examinées et discutées afin d'en arriver à un consensus. Grâce à une discussion explicite et à l'établissement d'une confiance, le professionnel de la santé, le patient et les membres concernés de sa famille peuvent développer une compréhension commune des buts et méthodes thérapeutiques appropriés.

**CONCLUSION** Une réflexion sur la nature culturelle des idées de la biomédecine au sujet du risque, de l'incapacité et de la normalité peut nous aider à comprendre qu'il existe plusieurs interprétations valides de ce qui est dans le meilleur intérêt d'un patient. Une réflexion personnelle fera en sorte qu'une communication respectueuse avec le patient et les membres intéressés de sa famille constituera le fondement des décisions sur les soins. La qualité des soins s'en trouvera globalement améliorée.

It is increasingly family physicians, rather than professional genetic counselors, who do the bulk of prenatal genetic counseling. There is a strong likelihood that there will be more demand for such services from family physicians as more genetic tests become available and waiting lists for genetic specialists become longer. Family physicians have expressed concern that they do not have adequate skills to provide effective genetic counseling.<sup>1,2</sup> Blaine and colleagues found that 49% of family physicians rated their baseline knowledge of prenatal genetics as poor before participating in a role-playing study. In particular, family physicians were not confident about their abilities to provide counseling and discuss the risks and benefits of genetic testing.<sup>3</sup>

Qualitative research with family physicians has shown that beliefs and values about genetic risk might vary among prenatal patients and between physicians and their patients; effective prenatal genetic counseling requires attention to the complex ways in which the meanings of risk and normality are understood.<sup>4-7</sup> Moreover, women who participate in prenatal counseling and testing might experience distress because of the counseling itself, which can in turn lead to unrealistic perceptions of their risk.<sup>8</sup>

The need for careful attention to how ideas about risk and normality are communicated is particularly true when communicating across cultures. Early social studies of genetic counseling have demonstrated that counselors and clients might misinterpret each other's statements and needs, particularly in cross-cultural encounters.<sup>9,10</sup> Based in part on those early observations, genetic counselors have known for some time now that training in cross-cultural counseling improves the provision of genetic testing services in multicultural settings.<sup>11-13</sup>

This article draws on the work of medical anthropologists to offer an approach to prenatal genetic counseling for family physicians working across cultures. Medical anthropologists have suggested ways to effectively offer health care across cultures without inadvertently perpetuating racist assumptions about cultural beliefs and behaviour.<sup>14</sup> More important, anthropologists have explained that there is no "recipe book" approach to cross-cultural health care; it is neither possible nor appropriate to rely on guides to the cultural beliefs of any given ethnic community, as there is as much variation within as between cultures. Relying on broad statements about culturally shaped health beliefs (eg, "the Tamils believe 'x' and therefore health care professionals should do the following ...") is precisely the wrong approach to take to effective cross-cultural health care. Rather, the key to a truly culturally sensitive approach is to recognize that all beliefs about health, including the values and practices of medicine itself, are culturally shaped.\* The application of this framework to prenatal genetic counseling requires family physicians to reflect on the beliefs and values of biomedicine in order to fully understand how patients' cultures might shape their decision making in prenatal care.

Now we will review the basic premises of prenatal genetic counseling and then offer strategies for cross-cultural counseling, using the case of Naseem as an example. **Table 1** is a proposed framework for genetic counseling in a cross-cultural setting.

\*Culture can be conceptualized as the web of meaning systems that shapes the lives of groups and individuals. Culture includes shared behavioural norms, social institutions, as well as beliefs and values. Culture helps to provide people with a worldview that gives meaning to their personal and collective experience. It influences all knowledge, production, and behaviour, including the knowledge and practices of science and medicine.

**Table 1. Proposed framework for genetic counseling in a cross-cultural setting**

FRAMEWORK	EXPLANATION
Organize knowledge in a coherent fashion while considering language differences	Important in pretest and posttest counseling in order to develop patient understanding of service and to understand patient's point of view Use paid and trained interpreters, not family members or untrained staff, whenever possible
Transfer health information from physician to patient while considering issues surrounding the following: <ul style="list-style-type: none"> <li>• trust</li> <li>• genetic abnormalities</li> </ul>	What are the relations of power between patient and provider? How can this be exacerbated in this specific context, and how might that affect decision making?  Cultural conceptions of disease and disability differ greatly: Which is worse, physical disability or mental disability? What conditions are associated with stigma, shame, pride?
Explain causes and effects while considering the purpose of screening	There are varying cultural conceptions of "risk": some patients might not want basic screening no matter how high the risk of an anomaly What does choice mean and does it matter to this family?
Alleviate discrepancies in patient's knowledge while considering the importance of autonomy	There can be substantial differences in autonomy and patient choice in non-European American tradition: Does counseling the patient or couple alone make sense in this family, or should others be involved?

## Sources of information

We searched PubMed and the Cochrane Database of Systematic Reviews. Evidence is mostly level II and some is level III, with the search encompassing the time period between 1995 and 2010. We used the following key words: *prenatal testing*, *culture*, and *ethnicity*.

## Prenatal genetic counseling

Prenatal genetic counseling involves counseling women<sup>†</sup> about the risk of chromosomal or genetic anomalies in developing fetuses. This includes the 3 following elements: general prenatal counseling on the prevention of birth defects (eg, prescribing folic acid supplementation to avoid neural tube defects); pretest genetic counseling as part of an offer of prenatal genetic testing; and post-test genetic counseling, following inconclusive or positive genetic test results.

There are multiple screening tests commonly used across Canada with no provincial consensus as to which is the best to use. The screens include first-trimester screening, maternal serum screening, integrated serum screening, and integrated prenatal screening. (For more information about prenatal genetic screening, visit the Society for Obstetricians and Gynaecologists of Canada website at [www.sogc.org/index\\_e.asp](http://www.sogc.org/index_e.asp)).

These screens use a combination of measurements of the hormones human chorionic gonadotropin,  $\alpha$ -fetoprotein, and unconjugated estriol, dimeric inhibin A, and pregnancy-associated plasma protein A, with ultrasound findings such as nuchal translucency to provide more accurate risk numbers with regard to having a child with Down syndrome or trisomy 18 syndrome, as well as open neural tube defects.<sup>‡</sup> Risk of chromosomal abnormalities is determined relative to age. If the risk is elevated above a predetermined cutoff, then the screen test result is positive. Women's health care providers (eg, family physicians, obstetricians, nurse practitioners, or midwives) receive the test results. They inform their patients of the results and counsel them in decision making; this usually involves discussing the possibility of confirmatory testing, which might be more invasive than the screen (eg, amniocentesis).

Most women prefer to be fully informed with regard to prenatal screening. Besides expecting quality information from their health care providers, women's decisions are also heavily influenced by personal values and social supports. They expect unbiased, high-quality information delivered in a timely manner at critical times during the decision-making process.<sup>5,7</sup>

<sup>†</sup> The term *women* will be used to mean clients of counseling throughout this document. In fact, it might be couples, women with support people, or women with their families who are the "clients" of prenatal genetic counseling.

<sup>‡</sup> Spina bifida, unlike the chromosomal anomalies, is considered to be of multifactorial origin because there are multiple reasons for the anomaly, many of which are not considered to be strictly genetic or chromosomal, like Down syndrome is.

## Communication

Good communication requires proper interpretation, which is important with every patient. However, it is of particular importance when the patient is of a different culture and speaks a different language. The goal of interpretation is to have a conversation between the clinician and the patient that enables each to understand and clarify any difference in assumptions about health status and expectations.

Translation is a challenge in all aspects of health care, but it is particularly challenging in time-sensitive contexts such as prenatal counseling, owing to the limited amount of time that is available to make decisions and carry out corresponding tests and procedures. Many prenatal tests and procedures (such as first- and second-trimester screening and diagnostic procedures such as chorionic villus sampling and amniocentesis) can only be performed at specific points in time during pregnancy; certain results, such as those from an amniocentesis, require a waiting period, which further exacerbates the need to have discussions and make decisions about prenatal testing in a timely manner.

**Family members as translators.** In general, family members are deemed inappropriate interpreters for sensitive and value-laden discussions, as their own values and beliefs might distort the information. However, we must recognize that oftentimes family members or unpaid or untrained community members are the only ones available and they might have to take on the role of translators. If this is the case, then every possible effort must be made to locate a trained translator, even by telephone. If this is not possible, then the next step is asking patients to indicate who they prefer to translate (eg, family member, friend).

**Translating culture.** Interpreting involves more than the translation of words.<sup>15</sup> This is particularly true in genetic counseling, in which understanding complex risk statistics and clarifying deeply held convictions in relation to risk are key to informed decision making. A patient might understand a question being posed but might have a different interpretation of the underlying meaning than that of the physician,<sup>16</sup> something that is not easily accommodated through the translation process. It is difficult to translate culturally specific illness meanings to Western biomedical language. In order to do so, interpreters are left on their own to provide an equivalent interpretation.<sup>17</sup>

The possibility of incomplete assessment or inappropriate treatment as a result of the translation process is a serious concern; and equally important are concerns around the accurate disclosure and translation of social and psychological factors. The demands placed on untrained volunteer interpreters are tremendous,

particularly if they are workers in the hospital and are pulled from their jobs to provide interpretation.

**Privacy.** Privacy concerns related to the use of interpreters are often complex. There are both advantages and disadvantages to using family members, community members, or anonymous strangers (eg, telephone translation services) as interpreters, depending on the context. While some families might prefer to be seen by clinicians or translators from similar cultural backgrounds, others might well be worried that this could compromise their privacy. These concerns can especially exist in small communities; screening and testing might reveal the presence of stigmatizing health conditions, which are then discussed with interpreters present. Privacy issues might extend well beyond the typical range of concerns raised. Indeed, one of the negative factors associated with using health care professionals from the same community as the patient (or family), or using translators from the same community as the patient (or family), is the private nature of health information. For example, in cultural contexts where marriages are arranged, stigma around certain medical conditions might make a child unsuitable for a good marriage later in life. Privacy is a challenge in communities where trained translators are not readily available. Thus, obtaining the help of trained translators via telephone would be of importance if privacy from families and communities is of utmost importance to patients. A referral to a tertiary health care centre where interpretation services are available might be warranted, depending on the gravity of the situation.

**Power relations.** In some cultural contexts, it might be considered inappropriate to discuss one's fears, concerns, or values outside of the family. Extreme differences in social status (social rank, caste, class) might be of great enough concern to mean a reluctance to fully disclose health information.

Interpreters cannot be assumed to be completely neutral or value-free conveyers of health information. Kaufert and Putsch illustrated that guidelines to convey language meaning accurately and in a value-free manner "often fail to take into account issues of class, power, disparate beliefs, lack of linguistic equivalence, or the disparate use of language."<sup>18</sup> In some cases, it might indeed be more appropriate to have a family member as translator.

**Time allocation.** Counseling through an interpreter requires sessions to be booked with extra time in order to ensure the patient is fully informed. In many instances, the session can be extended for an undue amount of time. This creates a conflict of interest in terms of allocation of time for other patients. It is the responsibility of the physician to recognize this conflict and to find a way to balance the interests of one patient with the need to respond to waiting patients.

Use of telephone interpretation services is one solution to timely translation in cases in which discussions and decisions are needed immediately. Having available prenatal screening information pamphlets in a variety of languages will also facilitate communication in time-sensitive contexts.<sup>8</sup>

If you were in Dr Abraham's situation, you should rebook Naseem's initial pretest counseling session for a time when you are less rushed and an interpreter who is paid and trained is available. Ask Naseem if she prefers to have someone present with her, such as her husband. On the day of the appointment, give Naseem and the interpreter some time to get to know each other before you see her. Confirm with Naseem that the language is the correct dialect and that there are no privacy or power issues that might limit her ability to be open; rebook with a different interpreter if necessary.

Note that in many cases for prenatal testing, it might be appropriate for the patient to have a partner or other support person who is more functional in your language to act as an interpreter if resources for professional interpreters are limited.

### Concept of "risk"

During any genetic counseling session with a patient, conducting a risk assessment and communicating risk are necessary precursors to informed and autonomous decision making about genetic testing and subsequent prenatal care. However, risk is arguably one of the most difficult concepts to convey to patients (even to those who share European American conceptions of personhood and normality that underpin the notion of risk used by clinicians).

Most obviously, the terms *positive* and *negative* to describe test results might be misleading and will need to be explained appropriately: it is counterintuitive to many lay people that a positive test result means a greater risk of abnormality and a negative result means a lower risk. It is particularly difficult to convey the fact that no risk is absolute (that is, that an elevated risk is never 100% and a lowered risk never 0%) and that even in the absence of elevated risk there is a 3% general population risk of there being a birth abnormality. Before reporting screening results to the patient (as opposed to test results, which are usually more definitive), it is important to stress that the screening results do not necessarily mean anything is wrong with the baby and that it is more likely that the baby will be healthy.

The use of metaphor to explain risk (eg, comparisons to winning a lottery) might obscure rather than clarify, as the meanings of comparator risks are also

<sup>8</sup>English-language pamphlets being translated by patients' family members is not desirable, as this approach, similar to any use of family members as translators, might lead to biased or otherwise inappropriate translation.

context-sensitive. Similarly, the cost-benefit approach to decision making (eg, the risk of a chromosomal abnormality compared with the risk of miscarriage due to the procedure itself) is more familiar to those from industrialized countries compared with those from other countries.<sup>19</sup>

Terms such as *gene*, *DNA*, and *chromosome* must be used with care in discussions of risk. These terms have become part of public consciousness through media reports on a range of genetic issues, from stem cell research to hereditary breast cancer; patients might have preconceived notions of the meanings of these terms that are vastly different from their intended use in the prenatal counseling session. For example, Samerski notes that discussions of genes and chromosomes might cause some patients to deduce that the conversation is about their own genes and not their children's.<sup>19</sup> It is important that physicians take the time to explain and re-explain metaphors and terms used in relation to risk, as well as take the time to ask for clarification and feedback to ensure that the patient has understood.

Beyond the problem of misunderstanding risk statistics, there are multiple meanings to what a given risk result means to that individual. To a parent, risk in the context of prenatal testing is only meaningful when interpreted in the context of daily life. The use of simple examples to explain risk (eg, 0.5% of having a miscarriage compared to 99.5% of not having a miscarriage) does not imply a straightforward response to, or meaning attached to, that risk. Women routinely draw on their culturally shaped everyday knowledge, giving it priority over received medical information.<sup>20</sup> Everyday knowledge about risk might be shaped by life circumstances such as the woman's reproductive history (eg, if she has a history of repeated miscarriages, the risks of miscarrying from the procedure itself might overwhelm the risk of Down syndrome); by religious beliefs; by attitudes about disability; and by other information about risk (eg, Rapp demonstrated that in communities with a high rate of fatality from gang-related violence, women saw the risks of Down syndrome as quite low<sup>21</sup>). Therefore, as well as explaining the concept, it is important to understand the meanings, beliefs, and values that the woman gives to her understanding of the riskiness of life.<sup>22</sup>

Communication about the meaning of risk is far more challenging and important in cross-cultural risk communication than information about false-positive rates and detection rates, because it is the meaning of risk in the context of everyday life that shapes decisions about prenatal testing.

Ensure that Naseem understands the potential harms and benefits of genetic testing (as you should with all patients—whether or not they are culturally distanced from you). Listen, reframe, and listen again

to confirm that you understand Naseem's values and beliefs about risk in general and risk in relation to her unborn child in particular.

### Concept of "normal"

There is a danger in assuming that the culture of the patient can be identified and then a particular care plan can be developed in a specific cultural way. Culture shapes, but does not determine, beliefs and choices. Most parents want to give birth to normal babies, but the meaning of what is "normal" varies tremendously both within and among cultures.<sup>23</sup>

Rapp provides a striking example of the variation between parents in what is believed to be normal or acceptable in a child. Of 2 patients who had learned that their fetuses would be affected by Klinefelter syndrome (a nonlethal sex chromosome aberration often resulting in some degree of mental retardation), one patient chose to abort and the other decided to continue with the pregnancy. The first patient told her counselor, "If he can't grow up to have a shot at becoming the President, we don't want him."<sup>21</sup>

The second patient said the following of her son:

He's normal, he's growing up normal. As long as there's nothing wrong that shows—he isn't blind or deaf or crippled—he's normal as far as I'm concerned. And if anything happens later, I'll be there for him, as long as he's normal looking.<sup>21</sup>

Culture plays a role in what is acceptable or desirable and what is unacceptable or undesirable in a baby. For example, within one cultural tradition a disabled child might be regarded as a blessing, but within another culture it might be regarded as the result of moral misconduct.<sup>22</sup> Culture also shapes whether diagnostic or preventive technologies are deemed to be useful or are ignored. For example, some religious traditions do not adhere to the belief that health care can be preventive, believing that health care should be initiated only after an injury has occurred or a disease has manifested.<sup>24</sup>

The harms or burdens of having a baby with a genetic abnormality might be a huge concern within communities where intermarriage is common. Within some Ashkenazi Jewish communities, if both partners in a couple are found to be carriers of a genetic mutation, this might affect whether the couple is permitted to marry.

It is important for a physician doing genetic counseling to explore the woman's own ideas of what is normal and acceptable, or abnormal and undesirable, from her own culturally shaped point of view. More important, while culture shapes the understanding and use of genetic testing, it is impossible to determine an individual's beliefs and choices about genetic testing by knowing his or her cultural group affiliation. The differences within cultural groups are likely as important as the differences among them.<sup>25</sup>

While talking with Naseem, take the time to listen, reframe, and listen some more. Hold up for scrutiny your own ideas about what is normal and desirable in a baby, and compare your own preconceived assumptions with those of Naseem's. Comparing both sets of assumptions makes it easier to ensure that you have elicited as much as you can from Naseem about her values, beliefs, and choices about genetic testing.

### Consider the decision makers

Autonomy, one of the cornerstone principles of informed consent, gives priority to the values and wishes of the individual patient. The North American understanding of the person as an independent individual and the associated moral valuing of autonomous decision making is not shared by most other cultures. Many ethnic groups in Canada and elsewhere adhere to a collective notion of self, in which interpersonal and social responsibility are more highly valued than individualism.<sup>26</sup> In many cultural traditions, health decisions are believed not to be best made by an individual but by a group, such as the family or community.

It is possible that the woman, or even the couple, might not have the only say in prenatal decisions. A woman might be accompanied by a relative or relatives who will make decisions about her and her baby's health care, and the woman might appear to be completely passive during the counseling session. It is equally possible that the person making the final decision, such as the husband, patriarch, or matriarch, will not even attend the session<sup>10</sup>; therefore, directing counseling to the patient in this type of situation is problematic.

Informed consent does not require that patients' decisions be uninfluenced by their cultural, social, or familial context. People from any cultural background will draw on their cultural and social context, as well as significant others, and they need to be able to trust health care professionals to support their decisions. This is not a violation of autonomy.

Do not assume that Naseem is the only decision maker or that she is a decision maker; equally, do not assume she is not, even if there is evidence to suggest otherwise. It might be a challenge for Canadian-born health care professionals to accept that the family patriarch, rather than the patient herself, might be the primary decision maker. Spend time with Naseem in the absence of other family members to ensure that she is making a decision that she is comfortable with. If Naseem requests to have someone else make decisions on her behalf, that is her right.

### Culture and power

There is a temptation to gloss all difference as cultural. Differences between the values promoted in


biomedicine and those held by non-Western patients with culturally or religiously shaped beliefs are likely to be minor compared with the barriers in communication posed by economic, educational, and political dimensions. In particular, cultural differences are not the only challenge to trusting relationships between patients and health professionals. Poverty, a history of oppression from authorities, and other social and historical factors can lead to mistrust even when there are no overtly apparent "cultural" differences. For example, a previous conflict with authorities or disappointment with health care can prevent parents from actively engaging in their children's health care, or can prevent patients from asking direct questions. Encouraging active involvement in health care decisions will often require exploration of the personal history of these experiences, some of which might have been very traumatic.

New Canadians might have had clinical care only in response to urgent medical needs, rather than preventive care. These patients might be less likely to understand the premise of prenatal genetic counseling sessions. There is some variation in the practice of biomedicine around the world; new Canadians might expect a patriarchal system in which the medical professionals make the decisions, and thus they might not be familiar with the collaborative decision making that is standard in genetic counseling sessions.

Special consideration must be given to refugees. The effect of exposure to torture, organized violence, war, and violent authority figures in particular are challenges to a trusting practitioner-patient relationship. Signing a consent form, for example, might be perceived as a familiarly dangerous act for patients from repressive political regimes in which citizens associate signed documents with oppressive arms of the state. A history of exposure to torture might not be voluntarily offered by patients or families for whom acts of torture might have been performed by medical staff.<sup>27</sup>

### Conclusion

The values and beliefs of physicians, no less than those of patients, are shaped by culture. In promoting a patient's best interest, the assumptions of both patients and providers must be held up for examination and discussed in the attempt to arrive at a consensus. Through the explicit discussion and formation of trust, the health professionals, patients, and family members who are involved can develop a shared understanding of appropriate therapeutic goals and methods.

Reflecting on the cultural nature of biomedicine's ideas about risk, disability, and normality helps us to realize that there are many valid interpretations of what is in a patient's best interest. Self-reflection helps to ensure that respectful communication with the specific family and patient is the basis for health care decisions. This helps to improve the quality of care. 

**Ms Bhogal** is a current medical student at Memorial University in St John's, Nfld. **Dr Brunger** is an Associate Professor of Health Care Ethics in the Faculty of Medicine at Memorial University.

#### Contributors

Both authors contributed to the literature search and to preparing the article.

#### Competing interests

None declared

#### Correspondence

**Ms Ashvinder K. Bhogal**, Faculty of Medicine, Memorial University of Newfoundland, Health Sciences Centre, Prince Philip Dr, St John's, NL A1B 3V6; e-mail [ashvinderk@hotmail.com](mailto:ashvinderk@hotmail.com)

#### References

1. Qureshi N, Armstrong S, Modell B. GPs' opinions of their role in prenatal genetic services: a cross-sectional survey. *Fam Pract* 2006;23(1):106-10. Epub 2005 Aug 22.
2. Aalfs C, Smets EM, de Haes HC, Leschot NJ. Referral for genetic counseling during pregnancy: limited alertness and awareness about genetic risk factors among GPs. *Fam Pract* 2003;20(2):135-41.
3. Blaine SM, Carroll JC, Rideout AL, Glendon G, Meschino W, Shuman C, et al. Interactive genetic counseling role-play: a novel educational strategy for family physicians. *J Genet Couns* 2008;17(2):189-95. Epub 2008 Jan 30.
4. Hunt LM, de Voogd KB, Castañeda H. The routine and the traumatic in prenatal genetic diagnosis: does clinical information inform patient decision-making? *Patient Educ Couns* 2005;56(3):302-12.
5. Carroll JC, Brown JB, Reid AJ, Pugh P. Women's experience of maternal serum screening. *Can Fam Physician* 2000;46:614-20.
6. Nagle C, Lewis S, Meiser B, Gunn J, Halliday J, Bell R. Exploring general practitioners' experience of informing women about prenatal screening tests for foetal abnormalities: a qualitative focus group study. *BMC Health Serv Res* 2008;8:114.
7. Potter BK, O'Reilly N, Etchegary H, Howley H, Graham ID, Walker M. Exploring informed choice in the context of prenatal testing: findings from a qualitative study. *Health Expect* 2008;11(4):355-65. Epub 2008 Sep 16.
8. Tercyak KP, Johnson SB, Roberts SF, Cruz AC. Psychological responses to prenatal genetic counseling and amniocentesis. *Patient Educ Couns* 2001;43(1):73-84.
9. Paul N, Kavanagh L, editors. *Genetic services for underserved populations. Proceedings of the National Symposium on Genetic Services for Underserved Populations, Arlington, Virginia, May 1989*. Washington, DC: National Center for Education in Maternal and Child Health; 1990.
10. Browner CH, Preloran HM, Casado MC, Bass HN, Walker AP. Genetic counseling gone awry: miscommunication between prenatal genetic service providers and Mexican-origin clients. *Soc Sci Med* 2003;56(9):1933-46.
11. Dorman E, Michie S, Hooper R, Marteau TM. Low uptake of prenatal screening for Down syndrome in minority ethnic groups and socially deprived groups: a reflection of women's attitudes or a failure to facilitate informed choices? *Int J Epidemiol* 2005;34(2):346-52. Epub 2005 Feb 28.
12. Pinales-Morejon D, Rapp R. Ethnocultural diversity and genetic counseling training: the challenge for a twenty-first century. *J Genet Couns* 1993;2(3):155-8.
13. Weil J, Mittman I. A teaching framework for cross-cultural genetic counseling. *J Genet Couns* 1993;2(3):159-69.
14. Lock M. Introduction. In: Lock M, Gordon D, editors. *Biomedicine examined*. Dordrecht, The Netherlands: Kluwer Academic Publishers; 1988. p. 3-10.
15. Kaufert JM. Sociological and anthropological perspectives on the impact of interpreters on clinician/client communication. *Sante Culture Health* 1990;7(2-3):209-36.
16. Lee R, Rodin G, Devins G, Weiss MG. Illness experience, meaning and help-seeking among Chinese immigrants in Canada with chronic fatigue and weakness. *Anthropol Med* 2001;8(1):89-107.
17. Hsieh E. Interpreters as co-diagnosticians: overlapping roles and services between providers and interpreters. *Soc Sci Med* 2007;64(4):924-37. Epub 2006 Nov 28.
18. Kaufert JM, Putsch RW. Communication through interpreters in healthcare: ethical dilemmas arising from differences in class, culture, language, and power. *J Clin Ethics* 2000;8(1):71-87.
19. Samerski S. The unleashing of genetic terminology: how genetic counseling mobilizes for risk management. *New Genet Soc* 2006;25(2):197-208.
20. Brunger F, Bassett K. Culture and genetics. In: Knoppers BM, editor. *Socio-ethical issues in human genetics*. Quebec, QC: Les Éditions Yvon Blais Inc; 1998. p. 1-42.
21. Rapp R. Chromosomes and communication: the discourse of genetic counseling. *Med Anthropol Q* 1988;2(2):143-57.
22. Finkler K. Illusions of controlling the future: risk and genetic inheritance. *Anthropol Med* 2003;10(1):51-70.
23. Press NA, Browner CH. Collective silences, collective fictions: how prenatal diagnosis testing became part of routine prenatal care. In:

#### EDITOR'S KEY POINTS

- It is often family physicians, rather than professional genetic counselors, who provide prenatal genetic counseling and discuss the risks and benefits of genetic testing with patients.
- Beliefs and values about genetic risk might vary among prenatal patients and between family physicians and their patients; effective prenatal genetic counseling requires attention to the complex ways in which the meanings of risk and normality are understood.
- The key to a truly culturally sensitive approach to prenatal genetic counseling is to recognize that all beliefs about health, including the values and practices of medicine itself, are culturally shaped. Family physicians need to reflect on the beliefs and values of biomedicine in order to fully understand how patients' cultures might shape their decision making in prenatal care.

#### POINTS DE REPÈRE DU RÉDACTEUR

- C'est souvent le médecin plutôt qu'un conseiller génétique professionnel qui donne aux patients les conseils prénataux et discute avec eux des risques et avantages des tests génétiques.
- Les croyances et les valeurs relatives aux risques génétiques peuvent varier parmi les patients et entre les médecins de famille et leurs patients; des conseils génétiques prénataux efficaces exigent qu'on porte attention aux différentes façons de comprendre ce que signifient risque et normalité.
- Pour dispenser des conseils génétiques prénataux d'une façon qui respecte vraiment les différences culturelles, il faut reconnaître que toutes les croyances au sujet de la santé, incluant les valeurs et modes de pratique de la médecine même, sont influencées par la culture. Le médecin de famille doit réfléchir aux croyances et valeurs de la biomedicine s'il veut bien comprendre comment la culture du patient peut influencer ses décisions dans les soins prénataux.

Rothenberg KH, Thomson EJ, editors. *Women and prenatal testing. Facing the challenges of genetic technology*. Columbus, OH: Ohio State University Press; 1994. p. 201-18.

24. Andrews JD. *Cultural, ethnic and religious reference manual for health care providers*. Winston-Salem, NC: Jamarda Resources; 1995.
25. Kaufert P. The "boxification" of culture: the role of the social scientist. *Sante Culture Health* 1990;7(2-3):139-48.
26. White GM, Kirkpatrick J, editors. *Person, self and experience*. Berkeley, CA: University of California Press; 1985.
27. Silove D. The psychosocial effects of torture, mass human rights violations, and refugee trauma: toward an integrated conceptual framework. *J Nerv Ment Dis* 1999;187(4):200-7.

\*\*\*